

Perceptions of Barriers and Facilitators of Cancer Early Detection among Low-Income Minority Women in Community Health Centers

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African-American and Hispanic women receive fewer indicated cancer early detection services than do majority women. Low rates of cancer screening may, in part, explain the disproportionately higher rates of cancer deaths in this population. The aim of this qualitative study was to explore through individual interviews the perceptions of barriers and facilitators of colorectal, cervical and breast cancer screening among 187 low-income, primarily minority women in four New-York-City-based community/migrant health centers. We identified various barriers and facilitators within each of these categories. Clinician recommendation was the most commonly cited encouragement to cancer screening. Other facilitators of cancer screening identified by patients included personal medical history, such as the presence of a symptom. The perception of screening as routine was cited as a facilitator far more commonly for mammography and Pap tests than for either of the colorectal screenings. Less commonly cited facilitators were insurance coverage and information from the media. The most common barriers were a lack of cancer screening knowledge, patients' perception of good health or absence of symptoms attributable to ill health, fear of pain from the cancer test and a lack of a clinician recommendation. Using standard qualitative techniques, patients' responses were analyzed and grouped into a taxonomy of three major categories reflecting: 1) patients' attitudes and beliefs, 2) their social network experience and 3) accessibility of services. This taxonomy may serve as a useful framework for primary care providers to educate and counsel their patients about cancer screening behaviors.

Key words: cancer screening ■ women ■ ethnic groups ■ community health centers ■ barriers ■ facilitator ■ primary healthcare ■ low-income population

BACKGROUND

Cancer from all causes is the second leading cause of death in the United States.¹ This burden is particularly high among blacks and Hispanics, as compared to Caucasians.² A continued increase in cancer deaths among low-income minority women is due, in part, to lower screening rates and later detection of cancer, with African-American and Hispanic women having some of the lowest rates of cancer screening.^{3,4} As such, efforts directed at increasing the cancer screening rates in low-income minority women are important in order to decrease the burden due to cancer deaths experienced by this population. Moreover, empirical evidence suggests that use of screening tests in routine medical care helps reduce cancer deaths and improve survival rates.⁵ An in-depth understanding of the factors associated with both appropriate utilization and underutilization of cancer screening services is a necessary first step in efforts aimed at increasing overall cancer screening rates. Ample literature is available on the beliefs and perceptions of cancer causes, its progression and treatment. However, little is known about patients' perceptions of cancer screening behaviors among low-income, minority women, 50 years and older for whom these services are most often recommended.⁶

As part of an NCI-funded cancer early detection study designed to improve rates of cervical, breast and colorectal cancer screening in this population, we conducted in-depth one-on-one interviews with low-income, primarily minority women followed in four New-York-City-based Community/Migrant Health Centers (C/MHCs) that are members of Clinical Directors Network (CDN)—a practice-based research network.⁷ The goal of this qualitative component of the larger study was to elicit and explore the perceptions of barriers to and facilitators of colorectal, cervical and breast cancer screening among this population. Unlike other studies, which are limited to single cancer screening behaviors, a unique

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aspect of our study is that we explored perspectives of patients from various backgrounds with regards to multiple cancer screening behaviors. We undertook a qualitative study based on individual interviews for the following reasons: 1) there is limited data regarding the cancer screening behavior in this patient population, and 2) qualitative methodology is particularly well-suited for an exploratory study for which previous literature is limited, and for generating hypotheses and models of human behavior.^{8,9}

METHODS

Participants

The target population for this study comprised women age 50–69 that were followed in the C/MHCs. Trained research assistants approached women in the waiting area who appeared to be in the targeted age range, introduced the project and then proceeded to obtain informed consent if the patient was receptive. Women who consented to be interviewed were first screened for eligibility. To be eligible, patients had to have at least one prior visit to the C/MHC where they were recruited; be between the ages of 50 and 69; be fluent in English, Spanish or Creole; and identify the C/MHC as their usual source of primary care. Recruitment was limited to women in the above-stated age range because they, for the most part, need screening for all three target cancers. Extending the age range to include younger women for whom Pap tests are recommended would have reduced the number of interviewees eligible for breast and colon cancer screening. Each patient interview took approximately 30–60 minutes to

complete and was conducted in English, Spanish or Creole (depending on the patient's preference) by trained research assistants with undergraduate degrees. All research assistants were blinded to patients' medical history. The study was reviewed and approved by the Institutional Review Boards of both Clinical Directors Network and Dartmouth Medical School.

Interviews

Patients were asked open-ended questions designed to explore the barriers and facilitators of cancer screening behavior based on the PRECEDE-PROCEED framework.^{10,11} According to this framework, factors affecting human behaviors are classified into predisposing, enabling and reinforcing categories, thus, making it possible to group the specific features of a given health behavior according to the types of interventions available in health education and health promotion. This framework is used to guide the development of health promotion interventions targeted at improving human behaviors in different healthcare settings.^{10,11}

Each patient interview was divided into sections focusing on a particular screening test [mammogram, Pap test, home fecal occult blood test (hFOBT) or sigmoidoscopy]. Patients who had never had a screening were asked a different set of questions than those who had been previously screened (Table 1). Patients who had been previously screened were only asked about facilitators, while patients who had not been screened were questioned about barriers and potential facilitators that might encourage them to be screened. All patients were

Table 1. Interview Questions on Barriers and Facilitators

Initial Question	Follow-Up Questions	
	To assess facilitators	To assess barriers
Have you ever had <this screening>?		
Yes	What encouraged you to have <this screening>?	—
No	What would encourage you to have <this screening>?	What has kept you from having <this screening>?
		Why haven't you considered having <this screening>?
Will you have <this screening> in the future?		
Yes	—	—
No	—	Why don't you plan to have <this screening> in the future?

Note: The name of each specific screening (mammogram, Pap test, hFOBT, and sigmoidoscopy) was used in interviews.

then asked if they planned to have that screening test in the future, and if not, barriers were assessed.

Qualitative Analysis

Patients' responses to the open-ended questions were entered into the computer verbatim and analyzed using basic content analysis.⁸⁻⁹ For this purpose, interview transcripts were read multiple times and responses coded into recurring concepts, which were then sorted and grouped into categories of similar content. The generated categories were grouped along two axes into those that hinder cancer screening behavior (barriers) and those that encourage cancer screening behavior in patients (facilitators). Finally, in order to provide context for patients' responses, we calculated the frequencies of the responses to each of the questions (Table 1).

RESULTS

Participants

A total of 187 women were interviewed out of 457 subjects who were approached for participation in the study. Of those approached, 14% refused consent, 26% were ineligible by age, 5% were ineligible because they were transient rather than established users of the C/MHC and 14% did not show up for a scheduled interview after agreeing to participate. Most patients had received at least one of the three

tests previously (178 patients had mammograms, 179 had Pap tests, 106 had hFOBTs and 35 had sigmoidoscopies). Of the 187 women interviewed, 44% were African-American, and 51% were Latina. About 39% had at least a high-school education. Of the 64 patients who provided information on their income status, 92% reported earning less than \$25,000 annually. The women interviewed indicated that most prior tests were for screening rather than for diagnostic reasons, accounting for over 90% of Pap tests and mammography (161 of 179 tests and 164 of 178 tests, respectively). Seventy-seven percent of home hFOBTs (82 of 106 tests) were for screening, while 49% of sigmoidoscopies (17 of 35) were done for diagnostic reasons.

Identified Categories of Cancer Screening Behaviors

Qualitative analysis of patients' responses revealed three major categories of cancer screening behaviors: 1) patient attitudes and beliefs, 2) social network experience and 3) accessibility of services. The themes underlying each of these categories were further subdivided into internal or external factors. Internal factors are defined as those factors that reflect a patient's desire or motivation to seek cancer screening (inherently related to the patient's cognition), while external factors are those factors that reflect a patient's ability to seek cancer screening (inherently

Table 2. Taxonomy of Patient Facilitators of and Barriers to Cancer Screening

Category	Facilitators	Barriers
<i>Patients' Attitudes and Beliefs</i>	Personal health/cancer history Reassurance about pain Recommended for women my age Screening is routine Seeking reassurance about health Wanting to care for one's self	Competing priorities Esthetics (don't like idea) Fatalism Fear of cancer diagnosis Fear of pain or unpleasantness from procedure Lack of cancer screening knowledge Loss of privacy/ embarrassment Low self-efficacy for the screening procedure Perception of good health/absence of symptoms Perception of not needing the test
<i>Social Network Experience</i>	Advice from family members Advice from friends Family history of cancer Information from the media Knowing someone with cancer Medical recommendation	Family discouragement Knowledge of someone harmed by test Lack of medical recommendation
<i>Accessibility</i>	Availability of insurance Affordability of screenings Convenient location of screening services	Cost of test Lack of transportation Language barrier

related to the patient's environment). As such, the categories of patient attitudes and beliefs were considered internal, while the categories of social network and accessibility of services were considered external. A taxonomy of all three categories as a compendium of issues that patients raised during the individual interviews is outlined in Table 2.

Internal Factors

Patients' attitudes and beliefs as facilitators.

The attitudes and beliefs identified as facilitators of cancer screening behaviors included personal fac-

tors, such as self-care, coping (wanting to take care of oneself), fear of cancer and information seeking/reassurance. For instance, one patient wanted to care for herself because of her role as a caregiver for other family members: "I need to take care of myself, because no one can take care of me." Another patient responded, "The kids I babysit depend on me."

For another patient, it was easy to seek cancer screening services, because it had become a routine practice for her: "When I turned 40, they said I should have one mammogram every year and I've been doing it ever since. I don't like surprises."

Table 3. Facilitators Cited by Women

*If tested previously, what encouraged you to have the specific test? **

	Mammogram n=178		Pap n=179		Home FOBT n=106		Sigmoid- oscopy n=35	
	N	%	N	%	N	%	N	%
<i>Patient Attitudes and Beliefs</i>								
Screening is routine/recommended for women my age	79	45	59	33	11	9	6	18
Wanting to care for one's self/seeking reassurance about health	55	31	60	34	11	11	4	11
<i>Social Network Experience</i>								
Medical recommendation	90	51	70	39	76	72	20	57
Personal health/cancer history	23	13	32	18	26	25	12	34
Family history of cancer	5	3	3	2	2	2		
Advice from family and friends/known someone with cancer	3	2	1	1	1	1		
Information from the media	3	2	2	1				
<i>Accessibility</i>								
Convenient location of screening/screening covered by insurance	2	2						
Don't know/other/no response	2	2	7	4	6	6	2	6

*If not tested previously, what would encourage you to have a home FOBT/sigmoidoscopy? **

	Home FOBT n=60		Sigmoidoscopy n=88	
	N	%	N	%
<i>Patient Attitudes and Beliefs</i>				
Wanting to care for one's self/seeking reassurance about health	8	13	13	15
Screening is routine/recommended for women my age	2	4	2	2
Reassurance about pain	1	2	2	2
<i>Social Network Experience</i>				
Medical recommendation	22	37	47	54
Personal health/cancer history	12	20	17	19
More Information	3	5		
Family history of cancer	3	3		
<i>Accessibility</i>				
Affordable cost	1	2		
Don't know/other/no response	20	33	16	19

* Women could mention more than one facilitator for each screening behavior. Among respondents, only seven had never previously had a mammogram and only four had never had a Pap test, so we do not present the frequencies of barriers to these two tests here, but discuss them in the text.

Whereas for other patients, cancer screening is important to provide reassurance that they do not have cancer. One patient responded, "I wanted to know for sure if I was okay or not."

Patients' attitudes and beliefs as barriers. The attitudes and beliefs identified as barriers to cancer screening included a lack of knowledge about cancer screening or cancer itself (patients never thought about screening or heard of screening test), a fear of cancer or pain, a perception of being healthy and not

needing the test, the harmful nature of the procedure (it causes pain, radiation and cancer), low self-efficacy or not having confidence in one's ability to carry out the test, the loss of privacy or embarrassment at having one's pelvic organs examined, and, finally, the potential disgust associated with touching one's stool. For instance, a patient said, "I don't like others touching my body," while another said, "I feel uneasy about body waste and fluid."

Regarding fear of the test procedure, several

Table 4. Barriers to Obtaining Colorectal Cancer Screening

For those not previously screened:

What has kept you from/Why haven't you considered having home FOBT/sigmoidoscopy?

	Home FOBT n=60		Sigmoidoscopy n=88	
	N	%	N	%
<i>Patient Attitudes and Beliefs</i>				
Lack of cancer screening knowledge	17	28	38	43
Perception of not needing the test/misinformation	22	37	26	29
Esthetics/don't like idea	3	5	3	3
Fear of pain	1	2	13	15
Low self-efficacy for the screening procedure	2	3		
<i>Social Network Experience</i>				
Lack of medical recommendation	8	13	9	10
Family discouragement			1	1
Knowledge of someone harmed by test			1	1
<i>Accessibility</i>				
Cost of test	1	2		
Language barrier	1	2		
Don't know/other	6	10	1	1

For those who indicate no intent to have a given test in the future:

*Why don't you plan to have a (specific test) in the future?**

	Home FOBT n=18		Sigmoidoscopy n=36	
	N	%	N	%
<i>Patient Attitudes and Beliefs</i>				
Perception of not needing the test/misinformation	5	28	15	42
Esthetics/don't like idea			4	11
Lack of cancer screening knowledge	1	6	4	11
Fear of pain	3	8		
Low self-efficacy for the screening procedure	2	11		
Competing priorities	1	6		
<i>Social Network Experience</i>				
Lack of medical recommendation	5	28	6	17
<i>Accessibility</i>				
Cost of test	1	6		
No transportation	1	6		
Don't know/other/no response	4	22	5	14

* Women could mention more than one barrier for each screening behavior. Only seven women indicated having no previous mammography and only four indicated no previous Pap. An additional two women who previously had received a Pap test indicated that had no intention to have another in the future. These results are discussed in text.

patients indicated that the pain associated with the procedure prevented them from doing the test, and one patient responded, "You should not do [the mammogram] too often because that is electricity."

A significant number of patients cited a lack of symptoms as a main reason for not having the test. One patient said, "Nothing is wrong with my breasts," and another said, "I have never felt any pains." Others had concerns about their ability to carry out the test properly, especially the hFOBT. One patient said, "I prefer for my doctor to do it. That way I know that it was done correctly."

External Factors

External factors were grouped into two broad categories: social network experience and accessibility of services, with social network experience playing a greater role in motivating patients to seek cancer screening. Social network experience is defined as a patient's reliance on information about cancer screening obtained from relatives or friends, while accessibility of services is defined as those factors related to the availability of screening services to patients.

Social Network Experience

Social network experience as a facilitator of cancer screening. Some patients regarded their friends or family as a source of encouragement to undergo cancer screening. The concepts grouped under this category included advice from family members (spouse, children or siblings), advice from friends, family history of cancer, knowing someone with cancer or other related health-promotion programs in the popular media. Another source of encouragement that was found to be even more important than advice from family and friends was medical advice from healthcare professionals, such as doctors, nurses or medical assistants.

Regarding the influence of friends, one patient said: "Well, I was talking to a friend, and she told me since I was 40 I should start getting one, and ever since then, I've gotten a yearly mammogram." Regarding a family history of cancer, another patient said, "My mom had cancer of the breast and as an obligation, I have to have the mammogram done every year." A majority of patients were encouraged to undergo cancer screening if their physician recommended it to them. One patient said, "I always

have it when my doctor tells me," and another said, "I listen to my doctor."

Social network experience as a barrier to cancer screening. Knowledge of someone who was harmed by the cancer screening procedure and discouragement from family or friends acted as hindrances to cancer screening for some patients. A patient reported not wanting to undergo screening sigmoidoscopy because of discouragement from a family member about the pain associated with the procedure: "My mom had one and she suffered a lot. It's painful."

Accessibility of Services

Accessibility as a facilitator of cancer screening. Issues related to the category of accessibility of services included a patient's insurance status or access to care, the availability of affordable screening services, having adequate transportation to screening sites, the location of screening sites, health provider availability and convenient C/MHC practice hours. Regarding cost, one patient said that she has a mammogram every year because her job provides free yearly mammograms.

Accessibility as a barrier to cancer screening. External factors, such as cost, a lack of transportation, and inconvenient practice locations, were cited as barriers to cancer screening. One patient said the following about the mammogram: "I don't want to go to another place for the exam. I don't want to travel. It [the screening site] should be easy to get to."

Frequencies of Barriers and Facilitators

In order to provide context for patients' responses, we calculated the frequencies of common responses to the open-ended questions asked during the interviews separately for each cancer screening. Tables 3 and 4 show the prevalence of the various concepts elicited from each open-ended question. Because most patients had previously had a mammogram and a Pap test, the number of women who were asked about barriers to these tests was quite low, and we do not present the frequencies of barriers for either test in the tables. As shown in Table 3, medical advice was the most common facilitator cited by patients across all three cancer screening behaviors, followed by routine medical care and car-

Enrollment in the Interview Process

457 patients were approached to participate in this study. 64 refused and 206 were excluded for various reasons including (age n=118; transient patients (n=23); and failed to complete any component of the interview (n=65). A total of 187 patients completed the interviews. Of the patients who completed the interviews, 185 had mammogram; 183 had Pap; 166 had hFOBT; and 123 had Sigmoidoscopy.

ing for one's self (mammography and Pap) and a patient's personal medical history (hFOBT and sigmoidoscopy). Less commonly cited facilitators included a family history of cancer and information from the media. If we take the individual screening tests, mammography and Pap smears had similar frequencies for all facilitators. All the factors listed in the table were less frequently cited as facilitators of colorectal cancer screening, except for medical advice and personal medical history. Personal medical history was a more frequently identified facilitator of colorectal screenings than of mammogram and Pap tests. In addition, many more patients considered mammogram and Pap as routine compared to colorectal screenings.

In general, patients cited fewer barriers than facilitators. As described above, because most patients interviewed had received at least one mammogram or a Pap test, only a small number of patients were asked about barriers to having these tests (those patients who had received a screening were not asked about barriers to having that test). The most commonly cited barrier to breast and cervical cancer screening behavior was the perception of not needing the test due to good health or an absence of symptoms attributable to ill health. For colorectal cancer, the perception of not needing the test due to good health or an absence of symptoms and a lack of knowledge were the main barriers cited for not obtaining or considering screening. Another important barrier elicited from patients was the fear of pain and fear of having the test. Fear of pain was the most commonly cited reason for not planning to have a mammogram in the future and the third most commonly cited reason for not having had a sigmoidoscopy. Lack of clinician recommendation and the perception of not needing the test were the two main reasons cited for not planning to have a hFOBT in the future. Other less frequently cited barriers included cost of screening test, lack of transportation, and not having enough time (competing priorities).

DISCUSSION

In this study, we explored the perspectives of 187 low-income and primarily minority women recruited in four C/MHCs, regarding factors that encouraged or hindered them from participating in cancer screening behaviors. Our findings suggest a taxonomy of barriers and facilitators of cancer screening in this underserved population. Barriers were grouped into three major categories of perceptions of cancer screening behaviors: patients' attitudes and beliefs, social network experience and accessibility of services.

Patients' attitudes and beliefs played a dual role either as a facilitator or a barrier to cancer screening in this population. Patients provided several explana-

tions why they underwent previous cancer screening, including it would "prevent them from having cancer," "would lead to quicker diagnosis of cancer" and "would prevent further deterioration." Such beliefs, which are consistent with a preventive-care paradigm, have been reported to be positively correlated with health outcomes in patients with other diseases, such as hypertension and diabetes.^{12,13} Other studies have found that cultural beliefs about harmful consequences of screening can act as powerful barriers to prevention,^{14,15} and some patients have been reported to have understandings of cancer that are divergent from the conventional biomedical paradigm,¹⁶ such as fear, misconceptions of who is at risk for specific cancers and the belief that "cancer screening tests were heralds of a disease that would ultimately lead to their death."¹⁷ Other fatalistic beliefs,¹⁸ such as "having cancer is like getting a death sentence", "cancer is God's punishment", and that "...there is very little one can do to prevent getting cancer,"¹⁹ also hindered women from seeking screening. Additional reported barriers included the painful nature of the screening test and embarrassment.²⁰

The second major category of perceptions of cancer screening behavior elicited in our study was patients' social network experience, which included two major social network influences: patients' immediate family and friends and their medical providers. In the present study, recommendation from a physician was cited across all tests as the most important facilitator of cancer screening. Some patients stated that friends and or family members' feedback about their experience with the cancer screening test served as a barrier to screening, while others stated that they were encouraged to seek cancer screening because they had relatives diagnosed with cancer and did not want to be in the same situation. Many women rely on friends and family networks as well as local healers as sources of health information^{21,22} and also as sources of referral and therapeutic network.^{23,24}

Social networks are important because they serve as a source of health information. Patients initially seek advice from their family and friends, then from local healers, and only after they have exhausted these sources do they go to the medical establishment.²⁵ Given these networks, efforts should be made to channel cancer health education for low-income and minority women provided by physicians and other medical providers through local churches and other faith-based organizations as well as through local media.²⁶⁻²⁹

Finally, the third category elicited was access to care, including the cost of care and lack of insurance,^{33,37} which were only infrequently cited as barriers to cancer screening in this study. Nevertheless,

these factors have been identified in prior studies as crucial to early detection of cancer.³⁰⁻³² Similarly, inadequate transportation and telephone services were implicated in other studies as barriers to screening for colorectal cancer^{34,35} and cervical cancer.³⁶

It is important to note the unique aspects and some limitations of this study. First, the results may not be generalizable, because this was a convenience sample of four C/MHCs and 187 patients, and the participants may not be representative of the broader patient populations who receive care in other C/MHCs. Particularly, the overall rates of patients who had at least one of the three cancer screening tests (95% mammogram, 96% Pap and 57% hFOBT) were generally higher than the rates for similar populations in NYC,³⁸ and such high rates explain the fact that patients reported fewer barriers than facilitators. Furthermore, the participants in our study cited the C/MHCs as their usual source of care. Having a usual source of care has been strongly associated with receipt of cancer screening services.³⁹ The qualitative nature of this study does not allow for quantitative inferences to be drawn, since estimating the prevalence of the cancer screening behaviors noted in this study population and the prevalence of the identified barriers and facilitators would require a larger population-based study utilizing a more rigorous random sampling methodology.

Despite these limitations, a major strength of this study is its potential applicability to a diverse group of Latin-American and Caribbean-American Spanish-speaking patients, which are often omitted from research due to barriers of language and culture. The results of this study have important clinical and research implications. Clinically, the categories of barriers and facilitators of screening adherence that we generated in this study provide a useful framework for communicating with patients about cancer screening in a practice-based setting. Clinicians may do well to identify the barriers patients face, such as discussion surrounding issues of harm from tests, fear of being diagnosed with cancer and reassurance about the safety of the tests, before making specific screening recommendations. This framework also allows for a systematic discussion of the misconceptions patients may have about cancer and cancer screening tests in general. This framework can be used in future research to develop comprehensive multicomponent behavioral interventions for investigating issues of adherence to cancer screening tests in low-income and minority patients. Finally, the categories of barriers and facilitators generated from this qualitative study can be used to develop a testable patient-derived model of cancer screening behavior in low-income and minority women. Testing of such a model would highlight the dynamic relationship between

patients' beliefs and attitudes, social network experience and motivation for cancer screening.

CONCLUSION

In conclusion, we have derived a taxonomy of barriers and facilitators of cancer screening behavior among low-income, predominantly minority women attending community/migrant health centers in New York City. The proposed taxonomy may serve as a useful framework for developing interventions, patient education and counseling about cancer screening behavior in this population as well as providing a framework for cancer communication between clinicians and patients in settings, such as C/MHCs and other primary care practices serving low-income and minority women. Therefore, in caring for minority and low-income women, it is important for primary care providers to address these beliefs before recommending cancer screening tests. The taxonomy presented in this study can serve as a template or framework for addressing the beliefs patients may have in a systematic manner in primary care settings.

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